

DOCUMENT RESUME

ED 332 414

EC 300 276

AUTHOR Vosler-Hunter, Richard W.
TITLE Changing Roles, Changing Relationships:
Parent-Professional Collaboration on Behalf of
Children with Emotional Disabilities. Families as
Allies Project.
INSTITUTION Portland State Univ., OR. Research and Training
Center on Family Support and Children's Mental
Health.
SPONS AGENCY National Inst. of Mental Health (DHHS), Rockville,
MD.; National Inst. on Disability and Rehabilitation
Research (ED/OSERS), Washington, DC.
PUB DATE Sep 89
CONTRACT G00943517
NOTE 57p.
PUB TYPE Guides - Non-Classroom Use (055) -- Tests/Evaluation
Instruments (160)
EDRS PRICE MF01/PC03 Plus Postage.
DESCRIPTORS Change Strategies; Check Lists; Child Advocacy;
*Cooperation; Counselor Client Relationship;
*Emotional Disturbances; *Mental Health Workers;
*Parent Participation; *Teamwork

ABSTRACT

This handbook aims to help parents of emotionally disabled children and professionals serving emotionally disabled children to put the concept of collaboration into practice, to understand the barriers to collaboration, and to develop strategies to overcome those barriers and promote a working partnership. Factors that may influence or inhibit the process of collaboration are discussed. Elements of collaboration are outlined, such as mutual respect for skills and knowledge, and shared planning and decision making. Strategies toward collaboration are described, for implementation by parents, by professionals, and by parents and professionals jointly. An appendix contains checklists for effective parent-professional collaboration to be administered to professionals, parents, service providers, state agencies, and professional training programs. Another appendix lists 13 organizational resources, four training materials on parent-professional collaboration, and three handbooks for starting and maintaining parent support groups. (35 references) (JDD)

* Reproductions supplied by EDRS are the best that can be made *
* from the original document. *

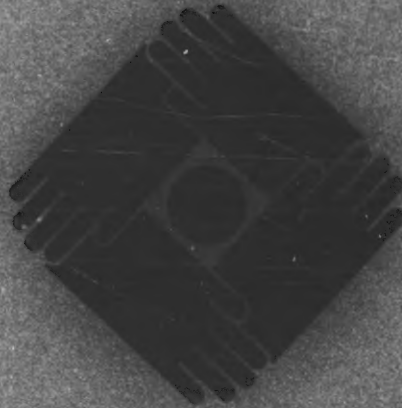
☒ This document has been reproduced as
received from the person or organization
originating it.

☐ Minor changes have been made to improve
reproduction quality.

• Points of view or opinions stated in this docu-
ment do not necessarily represent official
OERI position or policy.

CHANGING ROLES, CHANGING RELATIONSHIPS:

Parent-Professional Collaboration on Behalf of Children with Emotional Disabilities



Families As Allies Project
Research and Training Center on Family
Support and Children's Mental Health
Portland State University

BEST COPY AVAILABLE

ED332414

EC 300276

CHANGING ROLES, CHANGING RELATIONSHIPS:

Parent-Professional Collaboration on Behalf of Children with Emotional Disabilities

Richard W. Vosler-Hunter

Families As Allies Project
Research and Training Center on Family
Support and Children's Mental Health

Portland State University
Graduate School of Social Work
Regional Research Institute for Human Services
P.O. Box 751
Portland, Oregon 97207-0751
(503) 725-4040

September 1989

The recommended citation of this publication is:

Vosler-Hunter, R.W. (1989). *Changing roles, changing relationships: Parent-professional collaboration on behalf of children with emotional disabilities*, Portland, OR: Portland State University, Research and Training Center on Family Support and Children's Mental Health.

This publication was developed with funding from the National Institute on Disability and Rehabilitation Research, U.S. Department of Education and the National Institute of Mental Health, U.S. Department of Health and Human Services (NIDRR grant number G00943517). The content of this publication does not necessarily reflect the views or policies of these funding agencies.

TABLE OF CONTENTS

Introduction	1
The Context for Collaboration	3
Collaboration and its Discontents	7
Elements of Collaboration	15
Making It Happen: Strategies for Collaboration	26
Appendix A	34
Checklists for Collaboration	
Appendix B	42
Resources: Organizations and Publications	
References	46

INTRODUCTION

Over the past decade, the concept of parent-professional collaboration has gained increased credibility and support among both parents and professionals serving families. Acceptance of this philosophy of shared responsibility in the development and implementation of services for children is reflected in a growing body of professional literature and in the activities of parent self-help and advocacy groups. In addition, specific mandates and guidelines for parent involvement have been established in the field of special education through the passage in 1975 of Public Law 94-142, the Education for All Handicapped Act. Within the field of mental health services for children, parent-professional collaboration has been promoted through the Child and Adolescent Service System Program (CASSP) of the National Institute of Mental Health. This national initiative to support state efforts to develop comprehensive and innovative services for children with serious emotional disabilities and their families encourages family participation at all levels of program development, implementation and evaluation.

The Portland Research and Training Center on Family Support and Children's Mental Health has actively promoted the concept of parent-professional collaboration on behalf of children with emotional disabilities through its various research and training activities, most notably the Families As Allies Project. Over the past two years, the Families As Allies Project has developed training materials and a national training program to help parents and professionals examine attitudes and develop skills that enhance a working partnership. The experiences of this training project have shaped the views on collaboration expressed in this handbook. The author hopes that this handbook will be of help

to interested parents and professionals in their efforts to put the concept of collaboration into practice, to understand the very real barriers to collaboration that exist, and to develop strategies to overcome those barriers and promote a working partnership.

THE CONTEXT FOR COLLABORATION

"For most of our child's life, my husband and I have felt like we've been in a war with professionals, not a 'helping relationship'. It seems like what we know and want doesn't matter to them."

(mother of a child with an emotional disability)

"The idea is nice, but I find it very hard to do. A lot of parents don't realize my limits and expect the impossible or they don't care. It's nice to get a 'thank you' once in awhile."

(social worker in a community mental health clinic)

Developing effective treatment and related services for children with emotional or behavioral disabilities and their families is a difficult challenge for mental health and allied health professionals. The complex and varied nature of these disabilities, lack of a clear understanding as to the causes of emotional disabilities, and the absence of a coordinated and comprehensive service system are but some of the factors that contribute to the perception that "...public policy has dismally failed children with mental health problems" (Bergman, 1989).

For the parents of a child with an emotional disability, this public failure has intensified the stress they undergo in the struggle to find and pay for treatment for their child, cope on a day to day basis with the difficult behaviors and needs of their child, and maintain some sense of "normalcy" in their family and community. Parents' efforts to help their child and family are often further burdened by the common perception among some professionals and the society at large that the parents themselves have caused, or are in some way culpable for, their child's disability. Too often, the relationship between parents and the professionals serving the family is fraught with misunderstanding, suspicion, doubt, and conflict.

In response to these problems major initiatives at the federal, state and local level have been undertaken in recent years to develop comprehensive systems of service and care that are responsive to the needs of families whose children have serious emotional disabilities. One major force behind the growth of these efforts has been the Child and Adolescent Service System Program (CASSP) of the National Institute of Mental Health (NIMH). Since 1984, development of innovative services has been stimulated through the provision by CASSP of state and local grants for system building and demonstration activities. These efforts have been further enhanced by NIMH support for a Technical Assistance Center at Georgetown University Child Development Center and, with the National Institute on Disability and Rehabilitation Research (NIDRR) of the U.S. Department of Education, funding of Research and Training Centers in Oregon and Florida (Friesen, Griesbach, Jacobs, Katz-Leavy & Olson, 1988).

A guiding principle for the development of these services emphasizes that services should reflect the needs of the child and family, and that families of children with serious emotional disabilities must be full participants in all aspects of planning and delivering services (Friesen, Griesbach, Jacobs, Katz-Leavy & Olson, 1988; Stroul & Friedman, 1986). Since 1986, CASSP project funding has required that projects must include the family in both service planning and delivery (U.S. Department of Health and Human Services, 1986).

In concert with these formal systems efforts, the 1980's have witnessed the rapid development of organized parent advocacy efforts. The emergence of parent support and self-help groups specific to parents of children with emotional disabilities has provided new arenas for parents to obtain needed emotional support, information on their child's condition, and skills and opportunities to advocate for necessary services. As these groups develop and grow in numbers they will have a

profound impact on the traditional forms and ways in which parents and professionals have associated.

Interest in enhancing parent and professional partnership stems from the recognition that effective intervention by professionals must be based on an understanding and response to family identified needs and priorities. Dunst, Trivette, and Deal (1988, p. 8) note that "the focus on family and not professionally identified needs and aspirations as the target of intervention recognizes the family's rightful role in deciding what is most important and in the best interest of the family unit and its members." Similarly, Garbarino (1982, p. 72) concludes that "a family 'works' when its members feel good about the family, when their needs are being met, and the development of relationships flow smoothly."

This needs-based perspective of family support emphasizes that parents hold the primary and continuing responsibility for the caretaking, treatment, education and development of their children. In the absence of long term institutional care, parents of children with serious emotional disabilities assume these ongoing caretaking responsibilities throughout the child's life, often with only episodic professional service. Thus, effective help-giving for families must prioritize interventions that build on and support family strengths in meeting needs and promote the family's ability to acquire and sustain resources for problem solving. This collaborative framework, in which professionals are viewed as resources to the family, "emphasizes that family care-givers in their own right are capable diagnosticians (at least in terms of needs and services) and can carry major responsibilities for much of the treatment/rehabilitation process" (Moroney, 1986, p. 124).

Such a framework for viewing and understanding the needs of parents whose children have emotional disabilities illustrates the rationale for nourishing parent

and professional collaboration. This includes recognition that

Both parents and professionals possess critical information on the nature and course of the child's development and needs.

Parents have an intimate knowledge of their child and the experiences and needs of their families. Professionals possess specific skills and knowledge to help families solve problems and promote positive functioning.

Parents and professionals share a mutual goal of helping the child cope and adapt, and move into adulthood with skills and emotional support that promote independence and responsibility.

As primary caretakers, parents have a lifelong commitment to the growth and development of their child. As professional involvement is usually time limited when viewed over the course of the child's life, intervention must focus on strengthening family functioning and promoting self-sustaining skills, knowledge and support.

Collaboration will promote development of services that are flexible and appropriate to the unique needs of each family and child.

The shared expertise of parents and professionals allows both parties to gain greater insight into the nature of a child's particular disability, the needs of the child and the family, the types and forms of services needed, and the effectiveness of those services. At the levels of agency and public policy-making, collaboration can assist in identifying broad service needs of families, locate gaps in services, and provide a powerful lobby for instituting and funding effective programs for families.

COLLABORATION AND ITS DISCONTENTS

The philosophical appeal of collaboration and arguments for its necessity have been increasingly recognized in the professional literature. In the field of mental health, a substantial body of writings exists that argues for collaboration between professionals and parents of adult family members with chronic mental illness (for example, see Grunebaum and Friedman, 1988; Hatfield & Lefley, 1987; and Wasow & Wikler, 1983). Building on this previous work, a smaller but growing literature promoting collaboration is influencing children's mental health (Friedman, Duchnowski & Henderson, 1989; McManus & Friesen, 1986).

This primarily theoretical interest in the subject is buttressed by the practical benefits that it can provide to families. In a recent national survey concerning the needs and experiences of parents of children with serious emotional disabilities (Friesen, 1989a), 70 percent or more of the respondents identified as "very important" the role of professionals serving them in providing support to their child, providing support for the family, and making efforts to include them in decision making. Honesty with parents and the assumption of a respectful, non-blaming attitude by the professional were the most helpful characteristics identified. The effective delivery of services using such empowering perspectives and practices by professionals have also been demonstrated in studies and demonstration projects with families of young children and with parents whose children have physical and developmental disabilities (Cochran, 1987; Dunst, Leet & Trivette, in press; Karnes & Zehrback, 1975).

Despite the desire to develop collaborative relationships between professionals and parents of children with emotional disabilities, the success of such efforts appears uneven at best. While the variety and nature of individual characteristics that may interfere in the establishment of any particular partnership are

numerous, several overarching factors may be identified as influencing or inhibiting the process of collaboration. These factors include perceptions of the cause and nature of mental illness and emotional disabilities in children, the history and experiences of professionals and of parents with children who have emotional disabilities, cultural differences, and socio-economic influences.

Perceptions of Mental Illness and Emotional Disabilities

The beliefs of professionals and parents regarding the etiology (cause) of mental illness or emotional disability are very significant in shaping their attitudes concerning the possibility and even desirability of forming a partnership (Lefley, 1988; Terkelsen, 1985; Wintersteen & Young, 1988). Professional perspectives that view the parental role in the development of emotional disabilities in children as primarily pathological will clearly affect and limit the extent to which parents will be perceived as helpful or capable. Likewise, parents who believe that their child's emotional disability was somehow the result of bad or inadequate parenting, or who are burdened by the stigma of being the parent of a child with a disability, may suffer from a loss of self-esteem, experience social isolation, and feel inadequate as (or lacking the power to be) a partner in the treatment process.

Contemporary views of mental illness and emotional disability have been strongly influenced by psychoanalytic theory and practice. Early psychoanalytic theory held that mental illness was the result of damaged or distorted perceptions of reality, often due to hurtful childhood experiences and relationships with parents. As Grunebaum and Friedman (1988) note, "This view influenced clinicians to engage in individual psychotherapy with the patient and to avoid families altogether whenever possible." Over time, the pathological role of parents in causing mental illness in their children became widely accepted within the helping professions and professional training programs. Elaborate theories

explaining the role of parents (particularly the mother) in the causation of such illnesses as autism and schizophrenia were widely publicized. Terms such as "refrigerator mothers" and the "schizophrenogenic mother" were freely used and found in the literature (Grunebaum & Friedman, 1988; Lefley, 1988). More often than not, parents were viewed as either in need of treatment themselves, or at the minimum, an obstruction in the effective treatment of the ill family member.

While many, if not the majority of professionals now recognize that the exact roots of mental illness and emotional disability are unknown and likely to be found within a complex mix of biological, social and environmental factors, the pervasive view of family pathology continues to influence professional training and practice, as well as popular perceptions. Several reviews of the literature (Caplan & Hall-McCorquadale, 1985; Moroney, 1986; Wasow & Wikler, 1983) illustrate that unsubstantiated views of family pathology continue their influence on the field.

Such views of family pathology have not gone unnoticed or unfelt by parents. The stigma and guilt of having a child with a serious emotional disability can have a paralyzing and profound impact, particularly when placed upon the daily struggle to cope with the troublesome and often unpredictable behaviors of a child with emotional disabilities. Even more devastating, perhaps, is the distinct possibility that the parent may feel such stigma not only from interactions with professionals, but from other family members, relatives, and friends as well (Friesen, 1989b).

Experiences of Parents and Professionals

A number of environmental and emotional factors may form barriers for parents and professionals in their ability to establish an effective partnership.

These include such things as past negative experiences, family or agency environment, and resulting psychological barriers.

Given the complex nature of emotional disabilities in children and the lack of a cohesive and coordinated system to deliver services, it is not unusual for a family to be receiving services from a number of agencies and private providers simultaneously. In the absence of a coordinated approach, these services may be a source of added stress for the family. Contradictory service goals, frequent meetings with various providers, lack of clear expectations, and confusing or unclear communication between parents and providers may all serve to influence parents to view professionals with suspicion or anger. Dissatisfaction of parents with the way in which information is given to them by professionals, complaints that professionals fail to respect parents' expertise, and unreasonable delays in receiving services have been commonly noted in surveys with parents of children with other disabilities (Cunningham, Morgan & McGucken, 1984; Gallagher, Beckman & Cross, 1983; Lonsdale, 1987; Turnbull & Winton, 1981), and it is reasonable to believe that such experiences are equally (if not more strongly) felt by parents of children with emotional disabilities.

The daily demands of family life and caring for a child with a serious emotional disability may also present barriers for parents. The physical and psychological toll of this twenty-four hour caretaking may tap the emotional and physical ability of parents to engage in active partnership with professionals. In addition to coping with the needs and behaviors of the child with an emotional disability, parents may need to expend energy meeting the needs of siblings, caring for elder relatives, and finding the time and opportunity to maintain relationships with friends, co-workers and relatives. Lack of resources such as respite and child care, transportation, and appropriate education for their child may also affect the capacity of parents to work effectively with professionals.

Professionals also face barriers not dissimilar to parents. The multiple needs presented by some families, large caseloads and limited resources place great demands on the time and energy of professionals. The level of time and commitment needed to develop a close partnership with parents may seem daunting or unrealistic. Agency policies and regulations that limit the type, location and extent of contact professionals can make with families may also frustrate attempts at collaboration. Laws and policies concerning confidentiality may limit the type and extent of information professionals can give to or receive from parents.

As many families may not seek assistance until they have exhausted their own resources, professionals often face situations in which families may be in a state of desperation, seeking immediate relief for their child and family. In response to such crises, professionals may not have the time or inclination to fully communicate with the family and receive a more complete understanding of the family's situation and needs. Likewise, lack of clear communication and an understanding of the demands and stress experienced by the family may lead the professional to misinterpret the motives of parental behavior. For example, as parents traverse the complicated mental health system, they may approach many service providers seeking assistance. Professionals may view this as negative "shopping behavior" despite evidence that such behavior may be due to the mere inability of parents to find needed services (Olson, et. al., 1983). Or, the reluctance of parents to participate in professionally prescribed programs such as parent training or family therapy may be seen as examples of "resistant" or "hostile" behavior. The use of such labels may overlook alternative explanations such as other demands on the parent's time or lack of resources enabling participation (Winton & Turnbull, 1981).

Professional training, which has often emphasized identification and intervention around professionally identified family or individual deficits, also

presents a barrier to collaboration. Services provided by professionals that are in response to perceptions of "family pathology" and overlook family needs and strengths preclude meaningful collaboration and may in fact take forms that have negative consequences for families (Dunst & Trivette, 1987; Wasow & Wikler, 1983).

The extent to which professionals (and parents) perceive the role of the professional as dominant, or as the expert in the relationship, will also present a barrier to collaboration. Petr (1988), in an examination of the worker-client relationship in social work practice, notes that even with the transcendence of a more general systems approach to helping over the traditional medical model, "...it (the systems perspective) maintains a basic cause-effect orientation with the view of the professional as the responsible, controlling person in the relationship...The worker remains an objective, cause-effect oriented, intervening expert" (p. 624). Petr goes on to argue that such an orientation limits the amount of reciprocity available between clients and professionals and perpetuates the dominant position of professionals in relationships.

Cultural Differences

Cultural factors and the extent to which professionals recognize and honor cultural difference are a vital component for effective collaboration. Cross, Bazron, Dennis and Isaacs (1989), in a review of the literature demonstrate the differential treatment that non-white children with serious emotional disabilities and their families receive in mental health, education and juvenile justice systems. Higher rates of out-of-home placement of minority children, inappropriate placements, and inappropriate diagnoses are but some of the problems encountered by minority families. The authors note in the face of such data, that "Cultural traits, behaviors, and beliefs will likely be interpreted as dysfunctions to be overcome" (p. 4).

The ability of professionals to recognize cultural differences, knowledge and resources, and provide services that are congruent with the family are essential ingredients of parent-professional collaboration. Again, as in the case of recognizing family needs and strengths, issues of training, agency policy, and service resources that are culturally competent will affect the relative success or failure of parent-professional collaboration.

Similarly, the cultural style of a family will influence how the family approaches and responds to relationships with professionals. Winton (1988) notes such factors as the role of community, religious and spiritual leaders in approving actions, beliefs toward treatment and the meaning of illness, patterns and styles of communication, and experiences with the dominant culture may affect the family's level of participation and extent of cooperation with professional change efforts.

Socio-economic Influences

Socio-economic status and educational levels of parents may also influence the ability or extent of collaboration. The ability to locate and secure resources for their child and family, the extent to which parents have access to or the ability to obtain information on their child's condition, and the level of informal social support available to the family may help or hinder the collaborative process. Additional caretaking and financial burdens may be felt by single parents, limiting the time and energy they can realistically expend in interactions with professionals.

Given All This, Why Try?

Considering the preceding (and partial) list of real and potential barriers, is it in fact reasonable to believe that collaboration between parents and professionals can exist? Given the successful efforts of parents and professionals in other fields

of disability, the growing commitment of federal and state policy makers to the philosophy of collaboration, and the mounting demands of parents and parent advocacy organizations for their involvement, the outlook is extremely positive and the goal is achievable. But to be successful, parents and professionals must understand: (1) what the elements of collaboration are; (2) what a collaborative relationship looks like; and (3) how to make the relationship work.

ELEMENTS OF COLLABORATION

Webster's Ninth New Collegiate Dictionary (1985) contains the following definition of "collaborate":

To work jointly with others or together...to cooperate with an agency or instrumentality with which one is not immediately connected (p. 259).

Clearly, the ability to work together requires a **relationship** in which two or more people are bound together by common purposes or goals. A successful relationship is one that not only shares a common goal, but is one in which partners share joint responsibilities and rights, are seen as equals, and can jointly contribute to the process.

How do these ideas translate into reality when it comes to collaboration between professionals and parents of children with emotional disabilities? Such a relationship can be very complex, influenced by the nature and degree of the child's disability, the impact of the disability on the family, the information and resources available to both the parents and the professional to cope with the disability, and the interpersonal skills that parents and professionals bring to the relationship.

One way to approach this question is to look at what professionals and parents of children with emotional disabilities themselves identify as helpful and unhelpful in working together. Since 1987, the Families As Allies Project has conducted several dozen training workshops with mixed groups of professionals and parents of children with emotional disabilities to develop skills for collaboration. Using a curriculum that promotes learning through participant interaction, the training solicits audience identified issues as a basis for skill development (Vosler-Hunter & Exo, 1987). One of the initial exercises in the workshops asks participants to identify what attitudes or behaviors parents and

professionals bring to the relationship that are helpful and not helpful. Despite the diversity of parents and professionals participating in the various workshops, the lists generated by this exercise were remarkably similar.

When groups of parents were asked to identify what professionals did that made them angry or dissatisfied, these were examples of common answers:

"Professionals blame us for our child's problems;"

"They don't listen to parents;"

"They don't recognize parents are experts;"

"Professionals don't share of themselves;"

"They don't give us information;" and

"They don't follow up on commitments."

When groups of professionals were asked the same question concerning parents, these were common responses:

"When parents choose not to follow through;"

"Parents expect a 'quick fix';"

"They blame professionals for problems;"

"Parents tell us what they think we want to hear;"

"They make excuses for not working;" and

"They don't share responsibility in solving the problem."

When parents were asked to identify what professionals did that they appreciated, several common themes resulted:

"They are natural, act real, talk openly;"

"They share experiences;"

"They are positive and willing to listen;"

"When we work as a team;"

"When we become advocates together for services;" and

"They recognize the parent's expertise and believe it."

Professionals responded to behaviors and attitudes they appreciated in parents in such statements as:

"They trust me enough to ask for help;"

"When they ask a lot of questions;"

"They take part in the treatment team;"

"They advocate for their children;"

"When they don't give up;" and

"When they are willing to listen."

Such anecdotal statements are similar to reaction found among professionals and parents of children with other types of disabilities or who have adult family members with mental illness (Grower, Johnson-Martin & Goldman, 1987; Hatfield, 1978; Lonsdale, 1978; Spaniol, Jung, Zipple & Fitzgerald, 1987; Winton & Turnbull, 1981). Issues of trust, communication, information sharing and equality appear central to developing a collaborative relationship.

Based on the experiences of these workshops with parents and professionals and through reviews of the literature, the Families As Allies Project identified a number of key elements that appear to promote collaboration. These include: (1) mutual respect for skills and knowledge; (2) honest and clear communication; (3) open and two way sharing of information; (4) mutually agreed upon goals; and (5) shared planning and decision making.

1. Mutual Respect for Skills and Knowledge

Central to the establishment of any relationship is the recognition that all members of the relationship *have equal value and worth*. Parents and professionals need to recognize and acknowledge the strengths and expertise that each possesses. By virtue of their status, parents are indeed experts on their child and family. No amount of interviewing or analysis can ever yield for the professional the unique understanding of the family that the parent can offer. Parents have a vast repertoire of skills and wisdom concerning what 'works' and what does not work with their child, how services help or hinder the family, and what needs the family have. Using specialized skills obtained through training and experience, professionals offer parents opportunities to obtain new knowledge about their child's condition and behavior, adapt or change methods and behaviors to be more successful, and try new ways to assist family functioning. Successful collaboration occurs only when parents and professionals blend these skills and knowledge, recognizing the unique contributions each brings to relationship.

2. Honest and Clear Communication

In many ways, respect is the result of partners being honest in their feelings and expectations, and clear and open in how they communicate their thoughts. Parents and professionals need to examine the biases and preconceptions they have towards each other and how those biases may inhibit honesty in communication. Truthful input and feedback is essential for both parties to be able to understand the needs of the family, generate strategies for help, and evaluate progress.

A major problem in communication is often lack of clarity or understanding between the involved parties. This can particularly be an issue when the language used by one is not understood by another. Professionals need to be especially aware of this problem when talking with families. Mental health professionals are

accustomed to using a specialized language unique to their profession, training, and agency setting. In addition, professionals often refer to programs or services by their acronyms, a bewildering "language" to parents or citizens who do not have the professional's familiarity with the system. The use of unfamiliar language can not only lead to misunderstanding and frustration, but can also leave parents feeling inferior or unable to contribute.

Similarly, it is important for parents to ask questions of professionals when they do not understand what is said or need further information or clarification. Professionals are highly dependent upon the information the family provides in order to understand what the family is experiencing and what they need. A continual process of information giving, questioning, and clarification will help parents and professionals be sure that they are indeed communicating.

How one communicates is as important as what one communicates. Questions or statements that are judgmental, moralizing, or directive will likely inhibit or shut down communication rather than stimulate it. Asking a parent, "Can you tell me about what kind of person Johnny is?" will provide parents an opportunity to share both strengths and concerns they have with their child more than asking, "Well, what seems to be Johnny's problem?" Or, asking a professional, "Could you tell me about your background and training regarding children?" will elicit a less defensive and more assuring answer than, "Just what do you know about kids like Johnny?"

Clear and open communication, when conducted in an atmosphere of respect and sensitivity to the other person, will provide a basis for mutual understanding and action between parents and professionals. Accurate and timely information sharing, openness to questioning and clarification, and a desire to share knowledge will help overcome many barriers in working together, and help parents and professionals work through disagreements or disappointments as they arise.

3. Two Way Sharing of Information

Beyond effective communication styles, the extent and nature of information that is exchanged between parents and professionals is extremely important. As noted previously in this paper, a major need expressed by parents is for information. Parents seek as much information as is available that can help them understand their child's condition, the nature and course of the disability, treatment strategies, and its long term consequences for the child and family. Information on how systems work, tips on how to negotiate with and between agencies, and information about where to obtain a broad range of resources needed by the family are also a common desire. A professional's sensitivity and responsiveness to the information needs of families and the family's reciprocal sharing of important information will greatly facilitate the collaborative process.

However, the access and sharing of information can raise several concerns for both parents and professionals. Mesibov and La Greca (1981) identify three major information issues that can raise difficulty between parents and professionals. The first issue concerns the parents' right to all relevant information concerning their child and the manner in which this information is communicated to them. The authors note that professionals must share such information in a way that is appropriate to the family's emotional state and level of understanding, avoiding professional language or jargon. The second issue concerns parental desires to limit professionals' access to and use of information, such as previously completed evaluations. Here, the authors comment that such actions may come from a concern by parents that disclosure of this information may bias or prejudice the professional in their dealings and subsequent evaluations of the child. Third, the authors raise the issue of the reluctance that some professionals may have in allowing parents to review case records and reports. They note that professionals may fear possible misinterpretation by parents or that professionals will be

reluctant to put in writing their observations and comments concerning the child and family.

Such issues pertaining to parents' rights to information concerning their child and professional uses of information are difficult and complex. They can be complicated by laws and policies related to confidentiality of information designed with the intent to safeguard the privacy of the child, family members and other sources of information. Further, the issue of the kind and extent of information required or needed by professionals comes into play. Given the number of professionals that families must interact with, how often must parents "tell their story" as a requisite for receiving services, and to what level of detail must parents recount their family's situation? Without access to previous evaluations or reports, and without complete information, how can professionals be expected to gain an adequate picture of the family's situations and needs?

While there are no easy answers to these questions, and the circumstances of their impact will vary with each relationship, several steps can be taken by parents and professionals to resolve or ease these problems. First, professionals and parents can acknowledge that both are seeking the best help they can provide the child with an emotional disability and make every attempt to trust that their joint actions will be towards that aim. Second, parents and professionals should openly discuss these and other potential information sharing problems early on and establish a strategy or procedure to use in resolving them. Third, parents, and especially professionals, should remain aware of the emotional and personal nature of information that is often disclosed and treat such information with sensitivity towards the family and child and the respect that it deserves.

Finally, information sharing is a two way street. Throughout the process of obtaining services for their child, parents are expected and required to disclose substantial amounts of information concerning their child and family, their

feelings, and their hopes and disappointments. Parents appreciate and feel at ease when professionals equally share information about themselves, their experiences, and their opinions. This desire to "connect" is a natural and necessary part of any relationship and should be carefully attended to by both parents and professionals.

4. Mutually Agreed Upon Goals

Too often, parent and professional relationships are characterized by a dominant professional role and a passive, recipient role for parents. Parents typically provide information to the professional who then, often after consultation with other professionals, develops a plan of action for the parent or family. The goals of the plan or the rationale for them may not be made explicit or clear to the family, and may or may not be seen of any value by the family. Parents may then follow the prescribed actions, regardless of their helpfulness, or fail to complete the assigned task, risking the perception of being "resistant" or "non-compliant." Whatever direction the family may go, the likelihood is that neither the family nor the professional will feel fully satisfied with the process.

A basic premise for collaboration is self-determination for families. That is, families should be assisted in ways that promote and maximize their independence and abilities to meet their needs. Reviews of literature on help-giving affirm the importance of this principle (Dunst, Trivette & Deal, 1988; Fisher, Nadler & DePaulo, 1983). As Dunst, Trivette and Deal assert, "Help is maximally effective when the aid and assistance provided by the help-giver *are congruent with the help-seeker's appraisal of his or her problem or need*" (p. 95, emphasis added).

By working together to set goals, parents and professionals can be better assured that their efforts will represent a shared commitment that has made use of the knowledge and expertise each can provide. Such efforts not only recognize the priority of the family in deciding what is most helpful to them, it relieves the professional of the unrealistic expectation and burden of "having all the answers."

Of particular importance in the setting of mutual goals, is the need for parents and all the professionals working with the family to communicate. As it is not unusual for parents with a child who has emotional disabilities to be involved with a number of professionals (eg. social workers, psychiatrists, pediatricians, teachers, and juvenile court workers), the potential for conflicting service plans is high. An organized and coordinated approach to integrating these various services will relieve the burden and stress on the family of responding to multiple demands of providers and avoid costly duplication of efforts or conflicts between providers.

5. Shared Planning and Decision Making

As in setting mutual goals, joint decision making between parents and professionals affirms the primary role of the family in what services they receive and how they are provided. A commitment to shared responsibility implies that parents should be involved in all phases of service provision, including the direct services provided to families and involvement of parents in the policy-making process of agencies. This commitment helps to insure that services are responsive to family and community needs and that gaps in services can be identified.

At the individual level, joint planning and decision-making can occur at the assessment, provision and evaluation phases of services. Professionals can encourage parents to attend and participate in case staffing and planning meetings, jointly develop service contracts, and ask for and act on their feedback on progress. Arranging meetings at times and places convenient to parents, being

aware of child care, transportation and other demands on the family, and assuming the role of a consultant and resource to the family will all enhance the success of joint action.

Parents can assist this process by learning about and acting on their rights and responsibilities as recipients of services. Maintaining records of reports on their child, correspondence, and contracts for services, and taking notes of meetings will help ensure that agreed upon services are performed and in keeping with joint decisions. Writing down questions or needs for information and service before meetings will help make sure that all the things important to the family are covered and acted upon. Parents can also take the initiative in requesting meetings or reconsideration of past decisions as changes in the family and child's circumstances occur.

At the policy level, agencies can include parents as representatives on advisory and policy boards and provide them with the support and information necessary to be full participating members. Work groups of professionals and parents can be established to work on particular problems or issues, or to make recommendations on ways that agency practice and environment can become more "family friendly." Close participation and cooperation with parent support and advocacy groups in developing services and policies can also ensure that the agency is responding to community and family needs.

Finally, parents and professionals must clearly communicate to one another the level of involvement and decision making with which they are most comfortable. Depending on the relative demands of everyday work and family life, parents may desire differing levels of involvement. For some parents, the demands of extensive involvement in service planning may be beyond their current energy levels and time. Professionals and parents need to negotiate to what extent the involvement will take place and explore alternatives where possible (such as identifying another

family member or friend who can serve as a representative and advocate for the family).

While certainly not the only factors involved in achieving collaboration, the above elements - mutual respect for skills and knowledge, honest and clear communication, open and two way sharing of information, mutually agreed upon goals, and shared planning and decision making - are basic building blocks upon which a collaborative relationship will develop and flourish. To put these building blocks together requires patience, desire and, above all, **commitment**. Collaboration can only occur when both parents and professionals believe their joint efforts can make a difference in helping the child, when they follow through on decisions for joint action, and when they remain committed to the process over the long run.

A Comment on the Role of Parent Self-Help/Advocacy Groups in Collaboration

The knowledge and involvement of parents and professionals with parent support and advocacy groups can also enhance collaboration at the individual level as well as with broader efforts to help children and families. Parent support groups offer families a unique source of emotional support that cannot be duplicated within the relatively isolated relationship between parents and a professional. Similarly, parent support groups are an additional source of information and education that can support and enhance the particular needs and efforts of the parent-professional relationship. Organized efforts by parents to work with professionals, agencies and public policy bodies to effect changes in policies and practice provide a forum for greater interaction and understanding between parents and professionals, and can serve to increase professionals' recognition of the value of parent involvement and contributions.

MAKING IT HAPPEN: STRATEGIES TOWARD COLLABORATION

Parent-professional collaboration is a reciprocal process. That is, both parents and professionals must be actively involved with each other giving and receiving information, sharing experiences and knowledge, assigning and fulfilling tasks, and evaluating successes and failures. To accomplish these responsibilities a number of strategies can be employed.

Strategies for Parents

1. Expand your sources of support.

In addition to seeking professional assistance for your child, locate other sources of emotional and social support. Talking to another parent whose child has an emotional disability, attending parent support group meetings, and keeping in close contact with friends and relatives will help you keep a perspective on your situation, offer ideas and information you may not know about, and reduce the feelings of being separate or isolated from others.

2. Keep an open mind.

We all have had negative experiences with professionals (and parents!). Try to suspend your past judgments and use the principles above to create a working relationship. Keep in mind that the vast majority of professionals do want to help in ways that make sense to you and your child.

3. Satisfy your needs for information.

Ask questions, keep records, and seek explanations for terms or language you don't understand. Ask the professional you are working with to recommend written materials, other persons or organizations where you can

obtain additional information. As needed, seek out other parents or parent support groups that can offer information on your child's disability. Often, parent support groups, hospitals or public and private agencies offer workshops or seminars that may be helpful to you in answering questions or raising issues you and the professional need to consider.

4. Know and act on your rights and responsibilities.

If you are working with a public or private agency, obtain a copy of their grievance procedures or other policies that pertain to your rights as a client. Review such policies with the professional you are working with early on so you both understand the ground rules, can identify potential problems, and develop strategies for resolving them. If you are working with a private provider, or there are no written policies, develop a written understanding with the person you are working with that is mutually agreeable to both of you.

5. Take an active role in the services for your child.

Be clear with the professionals you are working with that you want to be a partner with them in helping your child. Provide constructive feedback, both positive and negative, on the services you are receiving. Using the elements of collaboration previously described, work out with the professional the roles each of you can play in helping your child.

6. Provide information and offer suggestions.

Remember that you are an expert on your child and that the information you have concerning your child's and family's needs are important to share with the professional. Let the professional know what you have done that has worked as well as what has not worked. Think about what the needs of

all the members of your family are and work with the professional to obtain the resources needed.

7. Know your limits.

While collaboration means we are equals in how we work together, it doesn't mean that each partner can necessarily equally share the work and tasks that must be done. Be aware of the demands upon you that extend beyond your child and balance your time and energy accordingly. Negotiate with the professional what needs to be done, who can accomplish particular tasks, and how they will be accomplished. Make sure that the expectations you agree on with professionals are clearly understood, are reasonable, and are open to re-negotiation as your circumstances and needs change.

8. Recognize efforts by professionals.

Let the professionals you work with know that you appreciate their efforts and recognize their assistance and accomplishments. Most professionals appreciate receiving feedback that lets them know what they have done that is helpful, not just what is not helpful. Positive affirmations can help establish and maintain a healthy respect and working relationship. After you are finished working with a professional, consider keeping in touch with them and letting them know how you and your child are. Due to the usually time limited involvement professionals have with families, they often have no knowledge as to how events have unfolded, and are genuinely interested in hearing from you.

Strategies for Professionals

1. Recognize the uniqueness of every family.

Each family comes to you with a unique history and set of experiences, strengths and needs. Keep in mind that while many programs and services are defined and designed as categories, no family truly fits any one category or "type." Actively communicate with the family so that you truly understand each member's needs and experiences. Design services with the family that recognize these unique qualities, respond to their needs, and focus on their desires. Examine with the family the full range of resources, both formal and informal, that can be mobilized to assist the family. Be creative in the use of available services and blend them with resources you and the family can identify in other agencies, family members, and the community.

2. Keep a focus on family strengths.

Often, professional training and practice has operated on the identification of deficits or problems, and recognition and mobilization of the positive aspects of a family are easily ignored or overlooked. A primary focus on deficits may ultimately provide only discouragement and frustration for parents. Families possess a large reservoir of knowledge and skills that they can share with the professional in their efforts to help a child. By jointly helping families identify and use these strengths, and by assisting the family to develop new skills and knowledge, professionals can help foster a spirit of cooperation with parents that truly recognizes their contributions.

3. Value and act on the expertise of parents.

By viewing the knowledge of parents as complementary to their own specialized skills, professionals will gain important insight and

understanding of the family. Viewing parents as equals validates the dignity and respect that parents deserve, and will clearly signal to parents your desire to work with them. Actively solicit parents' opinions, information, and suggestions as to what they need for their family and what services are helpful. Offer your own opinions and suggestions. Where differences occur (and they often do) use sensitivity and common regard in resolving them.

4. Help parents find support from other parents.

Having a child with an emotional disorder is a difficult and emotionally exhausting situation for many families. The stigma that can accompany having a child with an emotional disorder can also act to isolate the family, affect self-esteem and limit their ability to have social contact with friends and relatives. Assisting parents to locate other parents in similar situations as sources of emotional support and information can be a major contribution by the professional. Provide information to parents on the availability of parent support groups or help them make contact with families you know who can offer this support. If there are no local support groups, try to provide opportunities for parents you are in contact with to get together and possibly assist them in forming a group. Provide or help the family identify resources such as child care and transportation that can enable them to attend meetings or get together with other parents.

5. Be honest about your abilities and limitations.

Many people may expect that you are "the" expert and have all the answers to their needs. Accepting this unrealistic burden and attempting to fulfill this role will likely exhaust and frustrate both you and the families you work with. In a sensitive and practical manner, talk with the family about

what you realistically think you can accomplish and where you may not have solutions. Work with the family to identify places or persons that may be able to provide the information and services you cannot. Acknowledging your limitations, as well as your abilities, will likely enhance your respect with the family as opposed to diminishing it.

6. Be aware of the demands you place on families.

Place yourself in the position of the families you work with and consider the various demands they have on their time and energy, and the capacities they have to meet your expectations and recommendations. Meet at times and places that are convenient and accessible to families and to which they mutually agree. If you ask them to attend a meeting, be on time and prepared to accomplish the tasks at hand. If families are involved in treatment interventions with the child, talk to them about whether the level of involvement is reasonable and realistic and make adjustments as necessary. Carefully check to see whether the services you are providing a family are actually increasing rather than decreasing stress.

7. Join with parents to be advocates for their child.

Professionals have access to information on services and resources that the ordinary parent or citizen does not. They are also intimately aware of the processes one must go through to qualify and obtain services, the people who have power and decision making abilities in agencies, and the "shortcuts" that can be used to obtain services. Professionals can help families navigate the complex system of services, provide information on how to obtain services, help them in applying for services, and intervene where possible to help families get needed services.

8. Listen.

Above all, perhaps, professionals need to listen carefully to what parents tell them. This basic skill of helping remains the most important when working with families. Allow parents the time, support and environment to tell their story, express their needs and desires, and provide you with complete information on their child and family. Show in words and deeds that you listen to them and value their input.

Joint Strategies for Parents and Professionals

1. Critically examine your attitudes and beliefs.

Take time to assess how your views concerning mental illness/emotional disability and the role of the family in its genesis affects your views and behaviors. If you are a professional, do your beliefs alter the way you perceive and work with families who have children with emotional disabilities from other families? Do your beliefs devalue the potential contributions parents can make, or do they affirm the strengths that families have to cope and adapt? If you are a parent, do your beliefs affect how you view your competence and role as a parent? Do your beliefs inhibit you from reaching out to others or affirm your family's right to fully contribute and function in the community? These are important questions for parents and professionals to consider separately and together, for the answers will greatly affect our ability to form a partnership.

2. Obtain information and training that will increase your skills.

Take advantage of workshops and in-service opportunities that take place in your community that build skills for collaboration between parents and professionals and share these experiences with others. Professionals can invite parents to agency or staff meetings to discuss the experiences and

needs of parents and their children, provide feedback and suggestions on services, and help agencies develop policies and practices that are responsive to what families want. Parent support groups can invite professionals to attend their meetings to learn more about the value of mutual support and to provide lectures or workshops on particular issues such as the use and effects of various medications, techniques of discipline, available community services, and other such topics. Or, they can join together to sponsor community forums or hearings to improve services for children and families and jointly organize concrete efforts for change.

3. Remember why we are collaborators.

Finally, we all should keep foremost in our minds and efforts the children whom we seek to help and lead to more fulfilling and rewarding lives. Our collaboration as parents and professionals, when grounded in our desire to help children and their families, will likely flourish and succeed.

APPENDIX A

CHECKLISTS FOR EFFECTIVE PARENT-PROFESSIONAL COLLABORATION

The following checklists were originally published in *Working Together: A Training Handbook for Parent-Professional Collaboration* (1987), by Richard Vosler-Hunter and Kaye Exo, Portland, OR: Research and Training Center on Family Support and Children's Mental Health, Regional Research Institute, Portland State University.

A CHECKLIST FOR EFFECTIVE PARENT-PROFESSIONAL COLLABORATION

For Professionals:

- * Have I put myself in the parent's place and mentally reversed roles to consider how I would feel as the parent of a child with an emotional disability?
- * Do I see the child/adolescent in more than one dimension, looking beyond the diagnosis or disability?
- * Am I able to keep in mind that the child/adolescent is a person whom the parent loves?
- * Do I really believe that parents are equal to me as a professional and, in fact, are experts on their child?
- * Do I consistently value the comments and insights of parents and make use of their reservoir of knowledge about the child's total needs and activities?
- * Do I judge the child/adolescent in terms of his or her progress and communicate hope to the parents by doing so?
- * Do I listen to parents, communicating with words, eye contact and posture that I respect and value their insights?
- * Do I ask questions of parents, listen to their answers and respond to them?
- * Do I work to create an environment in which parents are comfortable enough to speak and interact?
- * Am I informed about the individual child's case before the appointment or group session, placing equal value on the parents' time with my own time?
- * Do I treat each parent I come in contact with as an adult who can understand a subject of vital concern?
- * Do I speak plainly, avoiding the jargon of medicine, sociology, psychology or social work?
- * Do I make a consistent effort to consider the child as part of a family, consulting parents about the important people in the child's life and how their attitudes and reactions affect the child?
- * Do I distinguish between fact and opinion when I discuss a child's problems and potential with a parent?

Families As Allies Project, Research and Training Center on Family Support and Children's Mental Health,
Portland State University, Portland, Oregon.

Checklist for Professionals (continued)

- * Do I make every effort to steer parents toward solutions and resources, providing both written and oral evaluations and explanations as well as brochures about potential services, other supportive arrangements, and financial aid?
- * Do I tell each family about other families in similar situations, recognizing parents as a major source of support and information and, at the same time, respecting their right to confidentiality?
- * At the request of parents, am I an active part of their information and referral network, expending time and energy to provide functional contacts to points in the service system and to parent support networks?
- * Do I express hope to parents through my attitude and my words, avoiding absolutes like "always" and "never"?
- * Do I see as my goal for interactions with parents the mutual understanding of a problems so that we can take action as a team to alleviate the problem?
- * Do I actively involve the parents of each child in the establishment of a plan of action or treatment and continually review, evaluate and revise the plan with the parents?
- * Do I make appointments and provide services at times and in places which are convenient for the family?
- * When I make a commitment of action to the family, do I follow through and complete that commitment?
- * Do I obtain and share information from other appropriate professionals to insure that services are not duplicated and that families do not expend unnecessary energy searching for providers and services?

Questions for this checklist were stimulated by an article in *Social Work*, 32(4), 1987, by Rosemary Alexander and Patricia Tompkins-McGill, entitled: "Notes to the Experts from the Parent of a Handicapped Child."

Families As Allies Project, Research and Training Center on Family Support and Children's Mental Health,
Portland State University, Portland, Oregon.

A CHECKLIST FOR EFFECTIVE PARENT-PROFESSIONAL COLLABORATION

For Parents

- * Do I believe that I am an equal partner with professionals, accepting my share of the responsibility for solving problems and making plans on behalf of my child?
- * Am I able to see the professional as a person who is working with me for the well-being of my child?
- * Do I see as my goal for interactions with professionals the mutual understanding of a problem so that we can take action as a team to alleviate the problem?
- * Do I maintain a file of important documents and correspondence so that I have a complete history of services provided to my child and family?
- * Do I clearly express my own needs and the needs of my family to professionals in an assertive manner?
- * Do I state my desire to be an active participant in the decision-making process concerning services for my child and do I seek mutual agreement on the means to insure my involvement?
- * Do I take an active, assertive role in planning and implementing the Individual Education Program for my child?
- * Do I come to appointments having thought through the information I want to give and the questions I want answered?
- * Do I accept the fact that a professional often has responsibility for service coordination and communication with many families, including my own?
- * Do I treat each professional as an individual and avoid letting past negative experiences or negative attitudes get in the way of establishing a good working relationship?
- * Do I communicate quickly with professionals who are serving the needs of my child when there are significant changes or when notable situations occur?
- * Do I communicate with other parents, thereby reducing my isolation and theirs, and sharing my expertise?
- * Do I encourage the professionals involved with my child to communicate with each other and to keep me informed as well?

Checklist for Parents (continued)

- * When I have a positive relationship with a professional or an agency, do I express support for that professional or agency in the community?
- * When I make a commitment to a professional for a plan of action, do I follow through and complete that commitment?
- * Do I maintain realistic expectations of professionals, myself and my child, knowing that complete and definitive answers are unlikely when complex emotional and physical conditions of children are concerned?

Consultation for the preparation of this checklist was provided by Dr. Richard Angell, Director of Training, Division of the Child Psychiatry, Oregon Health Sciences University, and residents in the child psychiatry program. Dr. Angell is a member of the national advisory committee to the Research and Training Center on Family Support and Children's Mental Health, Portland State University.

A CHECKLIST FOR EFFECTIVE PARENT-PROFESSIONAL COLLABORATION

For Service Providers

- * Are there program goals which embody a commitment to parents as equals with professionals in a team approach to meeting the needs of children?
- * Do parents participating in collaborative committees represent a variety of racial, cultural, economic, educational and geographic backgrounds?
- * Do parents participating in collaborative committees include those who children have been newly diagnosed, those are experienced in identifying services, and those representing parent organizations and coalitions?
- * Are parents included along with professionals for inservice programs designed to build collaborative skills on an ongoing basis?
- * Are there preservice and inservice training programs for professionals which build their commitment to a team approach between professionals and parents?
- * Do both formal and informal procedures exist to ensure effective parent-professional collaboration at all levels of the organization? Some examples are:
 - Meetings scheduled at convenient times for families;
 - Meetings composed of equal numbers of parents and professionals; and
 - Reimbursement for parents' time, services, transportation and child care expenses.
- * Are there mechanisms for receiving information from parents and parent groups and for disseminating information to them?

Adapted from *A Checklist for Effective Parent/Professional Collaboration*, one of several checklists created by Terri L. Shelton, Elizabeth S. Jeppson, and Beverley Johnson in *Family Centered Care for Children With Special Health Care Needs*. This book was published in 1987 by the Association for the Care of Children's Health (ACCH), 3615 Wisconsin Avenue, NW, Washington, D.C. 20016.

Families As Allies Project, Research and Training Center on Family Support and Children's Mental Health, Portland State University, Portland, Oregon.

A CHECKLIST FOR EFFECTIVE PARENT-PROFESSIONAL COLLABORATION

For States

- * Do parents participate in collaboration with professionals in all levels of decision making and policy formation within the state?
- * Is there a written philosophy of care that clearly reflects the pivotal role of parents in the care of children with chronic illness or handicapping conditions, *including emotional disabilities*?
- * Is there a statewide coalition of parents and parent support groups that crosses disability lines?
- * Has the state health (*mental health, child welfare, juvenile justice, special education*) department developed effective mechanisms for receiving information from parents and parent groups and disseminating information to them?
- * Is there an easily accessible statewide information and referral system?
- * Do *state policy and local practice ensure that* parents have complete and ready access to their children's medical and other records?
- * Does *state policy* create procedures to coordinate services for individual families? Is there a single individual *at the local level* to assist the family in implementing the service plan?
- * Are there mechanisms within the state's funding system, such as respite care programs and model waiver programs, that support the family's efforts to care for their child at home?
- * Are services organized in ways that allow for flexibility and the changing and varied needs of children and families?

Adapted from a list reprinted in the April 17, 1987 issue of *Network News*, a publication of the Georgetown Child Development Center. The original list was published in the *ACCH Network*, 5(3), Fall, 1986, and was authored by Beverley Johnson, Elizabeth Jeppson and Terry Shelton. ACCH is the Association for the Care of Children's Health. Changes to the original are in italics.

Families As Allies Project, Research and Training Center on Family Support and Children's Mental Health, Portland State University, Portland, Oregon.

A CHECKLIST FOR EFFECTIVE PARENT-PROFESSIONAL COLLABORATION

For Professional Training Programs

- * Are there opportunities for professionals to learn directly from parents about their perspectives and support needs?
- * Do parents participate in the development of training programs for professionals?
- * Do preservice and inservice training programs provide instruction in the following areas?
 - Skills in working in collaboration as a team member with professionals of other disciplines
 - Service delivery models with policies and procedures for coordinating care among agencies and providers in the community
 - Family dynamics
 - Developing transitional goals and implementing them
 - Financing options for families
 - Support needs of families
 - Effectiveness and satisfaction level of parent to parent support groups
 - advocating for comprehensive community resources

Adapted from *A Checklist for Effective Parent/Professional Collaboration*, one of several checklists created by Terri L. Shelton, Elizabeth S. Jeppson, and Beverley Johnson in **Family Centered Care for Children With Special Health Care Needs**. This book was published in 1987 by the Association for the Care of Children's Health (ACCH), 3615 Wisconsin Avenue, NW, Washington, D.C. 20016.

Families As Allies Project, Research and Training Center on Family Support and Children's Mental Health, Portland State University, Portland, Oregon.

APPENDIX B

RESOURCES: ORGANIZATIONS AND PUBLICATIONS

Organizations

Research and Training Centers:

Research and Training Center on Family Support and Children's
Mental Health
Regional Research Institute
Portland State University
P.O. Box 751
Portland, Oregon 97207-0751
(503) 725-4040

Research and Training Center on Children's Mental Health
Florida Mental Health Institute
13301 North 30th Street
Tampa, Florida 33612
(813) 974-4500

Parent Support and Advocacy Groups:

Federation of Families for Children's Mental Health
1021 Prince Street
Alexandria, Virginia 22314-2971

National Alliance for the Mentally Ill -- Child and Adolescent Network
1901 Fort Myer Drive
Arlington, Virginia 22209

The National Mental Health Association
1021 Prince Street
Alexandria, Virginia 22314-2971

Other Organizations:

Association for the Care of Children's Health
3615 Wisconsin Avenue, N.W.
Washington, D.C. 20016

Child and Adolescent Services System Program Technical Assistance Center
Georgetown University Child Development Center
3800 Reservoir Rd., N.W.
Washington, D.C. 20007

Children's Defense Fund
122 C. St., N.W.
Washington, D.C. 20001

The Council for Exceptional Children
1920 Association Drive
Reston, Virginia 22091-1589

Mental Health Law Project
1220 Nineteenth St., N.W.
Washington, D.C. 20036

National Information Center for Handicapped Children and Youth
P.O. Box 1492
Washington, D.C. 20013

Office of Civil Rights
U.S. Department of Health and Human Services
330 Independence Ave., SW
Washington, D.C. 20201

Public Citizen Health Research Group
2000 P St., N.W.
Washington, D.C. 20036

Training Materials on Parent-Professional Collaboration

Building Partnerships Between Parents and Professionals: A training to facilitate collaboration between parents of children with emotional handicaps, mental health professionals and educators. Information on ordering this workshop curriculum is available through the Ohio Coalition for the Education of Handicapped Children, 933 High Street, Suite 106, Worthington, Ohio 43085.

Developing A Parent-Professional Partnership (1989), by Brian Bentley. Information on ordering this workshop curriculum is available through the New York Child and Adolescent Service System Program, New York State Office of Mental Health, 44 Holland Ave., Albany, New York, 12229.

Working Together: A Training Handbook for Parent-Professional Collaboration (1987), by Richard Vosler-Hunter and Kaye Exo. Information on ordering this collection of training materials is available through the Research and Training Center on Family Support and Children's Mental Health, Regional Research Institute, Portland State University, P.O. Box 751, Portland, Oregon 97207-0751.

Working Together: The Parent/Professional Partnership (1987), by Kathy Kelker. Information on ordering this one day workshop curriculum is available through the Research and Training Center on Family Support and Children's Mental Health, Regional Research Institute, Portland State University, P.O. Box 751, Portland, OR 97207-0751.

Handbooks for Starting and Maintaining Parent Support Groups

A Guide for Developing Self-Help/Advocacy Groups for Parents of Children with Serious Emotional Problems, by Richard Donner and Glenda Fine. Information on ordering this publication can be obtained from the Georgetown University Child Development Center, 3800 Reservoir Road, N.W., Washington, D.C. 20007.

How To Organize an Effective Parent/Advocacy Group and Move Bureaucracies. Information on ordering this publication can be obtained from the Coordinating Council for Handicapped Children, 407 S. Dearborn, Chicago, IL 60605.

Parents Together: A Manual for Leaders of Support Groups for Parents of Children Experiencing Emotional and Behavioral Disorders (1989), by Douglass Brownstone. Information on ordering this manual can be obtained from the New York Child and Adolescent Service System Program, New York State Office of Mental Health, 44 Holland Ave., Albany, New York 12229.

REFERENCES

- Bergman, G.T. (Ed.) (1989). Mental health policy developments in the child mental health field. *State Health Reports on Mental Health, Alcoholism, & Drug Abuse*, No. 44, Washington, D.C.: Intergovernmental Health Policy Project, George Washington University.
- Caplan, P.J. & Hall-McCorquadale, I. (1985). Mother-blaming in major clinical journals. *American Journal of Orthopsychiatry*, 55(3), 345-353.
- Cochran, M. (1987). Empowering families: An alternative to the deficit model. In K. Hurrelmann, F. Kaufmann & F. Losel (Eds.), *Social Intervention: Potential and constraints*. New York: Walter de Gruyter.
- Cross, T.L., Bazron, B.J., Dennis, K.W. & Isaacs, M.R. (1989). *Towards a culturally competent system of care*. Washington, D.C.: CASSP Technical Assistance Center, Georgetown University Child Development Center.
- Cunningham, C.L., Morgan, P.A. & McGucken, R.B. (1984). Down's syndrome: Is dissatisfaction with disclosure of diagnosis inevitable?. *Developmental Medicine and Child Neurology*, 26, 33-39.
- Dunst, C.J. & Trivette, C.M. (1987). Enabling and empowering families: Conceptual and intervention issues. *School and Psychology Review*, 16(4), 443-456.
- Dunst, C.J., Leet, E. & Trivette, C.M. (in press). Family resources, personal well being, and early intervention. *Journal of Special Education*.
- Dunst, C.J., Trivette, C.M. & Deal, A.G. (1988). *Enabling and empowering families*. Cambridge, MA: Brookline Books.
- Fisher, J.D., Nadler, A., & DePaulo, B.M. (Eds.). (1983). *New directions in helping: Vol. 1, Recipient reactions to aid*. New York: Academic Press.
- Friedman, R.M., Duchnowski, A.J. & Henderson, E.L. (Eds.) (1989). *Advocacy on behalf of children with serious emotional problems*. Springfield, IL: Charles C. Thomas.
- Friesen, B.J. (1989a). *Survey of parents whose children have serious emotional disorders: Report of a national study*. Portland, OR: Research and Training Center on Family Support and Children's Mental Health, Regional Research Institute, Portland State University.
- Friesen, B.J. (1989b). Parents as advocates for children and adolescents with serious emotional handicaps: Issues and directions. In Friedman, R.M., Duchnowski, A.J. & Henderson, E.L. (Eds.), *Advocacy on behalf of children with serious emotional problems*. Springfield, IL: Charles C. Thomas.
- Friesen, B.J., Griesbach, J., Jacobs, J.H., Katz-Leavy, J. & Olson (1988). Improving services for families. *Children Today*, 17(4), 18-22.

- Gallagher, J.J., Beckman, P., & Cross, A.H. (1983). Families of handicapped children: Sources of stress and its amelioration. *Exceptional Children*, 20, 161-163.
- Garbarino, J. (1982). *Children and families in the social environment*. New York: Aldine.
- Grunebaum, H. & Friedman, H. (1988). Building collaborative relationships with families of the mentally ill. *Hospital and Community Psychiatry*, 39(11), 1183-1187.
- Hatfield, A.B. (1978). The psychological costs of schizophrenia to the family. *Social Work*, 23(5), 355-359.
- Karnes, M. & Zehrback, R. (1975). Matching families and services. *Exceptional Children*, 41(5), 545-549.
- Lefley, H.P. (1988). Training professionals to work with families of chronic patients. *Community Mental Health Journal*, 24(4), 338-357.
- Lonsdale, G. (1978). Family life with a handicapped child: The parents speak. *Child: Care, Health and Development*, 4, 99-120.
- McManus, M. & Friesen, B.J. (1986). *Parents of emotionally handicapped children: Needs, resources, and relationships with professionals*. Portland, OR: Research and Training Center on Family Support and Children's Mental Health, Regional Research Institute, Portland State University.
- Merriam-Webster, Inc. (1985). *Webster's ninth new collegiate dictionary*. Springfield, MA: Merriam-Webster.
- Mesibov, G.B. & La Greca, A.M. (1981). Ethical issues in parent-professional service interaction. In J. Paul (Ed.), *Understanding and working with parents of children with special needs*. New York: Holt, Rinehart and Winston.
- Moroney, R.M. (1986). *Shared responsibility: Families and social policy*. New York: Aldine.
- Olson, D., McCubbin, H., Barnes, H., Larsen, A., Muxen, M. & Wilson, M. (1983). *Families: What makes them work*. Beverly Hills, CA: Sage Publications.
- Petr, C.G. (1988). The worker-client relationship: A general systems perspective. *Social Casework*, 69(10), 620-626.
- Spaniol, L., Jung, H., Zipple, A.M. & Fitzgerald, S. Families as a resource in the rehabilitation of the severely psychiatrically disturbed. In A.B. Hatfield & H.P. Lefley (Eds.), *Families of the mentally ill: Coping and adaptation*. New York: Guilford Press.
- Stroul, B.A. & Friedman, R.M. (1986). *A system of care for severely emotionally disturbed children and youth*. Washington, D.C.: CASSP Technical Assistance Center, Georgetown University Child Development Center.

- Terkelsen, K.G. (1983). Schizophrenia and the Family: II Adverse effects of family therapy. *Family Process*, 22, 191-200.
- U.S. Department of Health and Human Services, (January, 1986). *Program Announcement MH-86-15: Mental Health Services Demonstration Grants*. Washington, DC: U.S. Department of Health and Human Services.
- Vosler-Hunter, R.W. & Exo, K. (1987). *Working together: A training handbook for parent-professional collaboration*. Portland, OR: Research and Training Center on Family Support and Children's Mental Health, Regional Research Institute, Portland State University.
- Wasow, M. & Wikler, L. (1983). Reflections on professionals' attitudes toward the severely mentally retarded and the chronically mentally ill: Implications for parents. *Family Therapy*, 10(3), 300-307.
- Wintersteen, R.T. & Young, L. (1988). Effective professional collaboration with family support groups. *Psychosocial Rehabilitation Journal*, 12(1), 19-31.
- Winton, P.J. (1988). Effective communication between parents and professionals. In D.B. Bailey & R.J. Simeonsson (Eds.), *Family Assessment in Early Intervention*. Columbus, OH: Merrill.
- Winton, P.J., & Turnbull, A.P. (1981). Parent involvement as viewed by parents of preschool handicapped children. *Exceptional Children*, 48, 324-329.

Changing Roles, Changing Relationships: Parent-Professional Collaboration on
Behalf of Children with Emotional Disabilities

EVALUATION FORM

1. Who used *Changing Roles, Changing Relationships*? (Check all that apply)

____ Parent ____ Educator ____ Child Welfare Worker

____ Juvenile Justice Worker ____ Mental Health Professional

2. Please describe the purpose(s) for which you used the monograph?

3. Would you recommend use of the monograph to others? (Circle one)

Definitely Maybe Conditionally Under No Circumstances

4. Overall, I thought the monograph was: (Circle one)

Excellent Average Poor

Comments: _____

5. Please offer suggestions for the improvement of subsequent editions of this monograph:

We appreciate your comments and suggestions. Your feedback will assist us in our effort to provide relevant and helpful materials. Thank you.

Please fold, staple and return this self-mailer to the address listed on the reverse side.

fold and staple



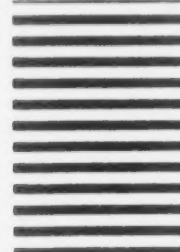
NO POSTAGE
NECESSARY
IF MAILED
IN THE
UNITED STATES

BUSINESS REPLY MAIL

FIRST CLASS PERMIT NO. A-75 PORTLAND, OREGON

POSTAGE WILL BE PAID BY ADDRESSEE

RESEARCH AND TRAINING CENTER
REGIONAL RESEARCH INSTITUTE FOR HUMAN SERVICES
PORTLAND STATE UNIVERSITY
P.O. BOX 751
PORTLAND, OR 97207



Research and Training Center Resource Materials

- ☐ *Annotated Bibliography. Parents of Emotionally Handicapped Children: Needs, Resources, and Relationships with Professionals.* Covers relationships between professionals and parents, parent self-help, support and advocacy groups, parent participation, parents' problems and guidelines. \$7.50 per copy.
- ☐ *Annotated Bibliography. Youth in Transition: Resources for Program Development and Direct Service Intervention.* Transition needs of adolescents: educational and vocational issues, programs and curriculum, research overviews, interpersonal issues, skills training. \$6.00 per copy.
- ☐ *Child Advocacy Annotated Bibliography.* Includes selected articles, books, anthology entries and conference papers written since 1970, presented in a manner useful to readers who do not have access to the cited sources. \$9.00 per copy.
- ☐ **NEW!** *Choices for Treatment: Methods, Models, and Programs of Intervention for Children With Emotional Disabilities and Their Families. An Annotated Bibliography.* The literature written since 1980 on the range of therapeutic interventions used with children and adolescents with emotional disabilities is described. Examples of innovative strategies and programs are included. \$6.50 per copy.
- ☐ *Families as Allies Conference Proceedings: Parent-Professional Collaboration Toward Improving Services for Seriously Emotionally Handicapped Children and Their Families.* Held in April 1986 and attended by delegations from thirteen western states. Includes: agenda, presentation transcripts, biographical sketches, recommendations, worksheets, and evaluations. \$7.50 per copy.
- ☐ *Gathering and Sharing: An Exploratory Study of Service Delivery to Emotionally Handicapped Indian Children.* Findings from Idaho, Oregon, and Washington, covering current services, successes, service delivery barriers, exemplary programs and innovations. \$4.50 per copy.
- ☐ *Glossary of Acronyms, Laws, and Terms for Parents Whose Children Have Emotional Handicaps.* Glossary is excerpted from the *Taking Charge* parents' handbook. Approximately 150 acronyms, laws, and words and phrases commonly encountered by parents whose children have emotional disabilities are explained. \$3.00 per copy.
- ☐ **NEW!** *Interagency Collaboration: An Annotated Bibliography for Programs Serving Children With Emotional Disabilities and Their Families.* Describes local interagency collaborative efforts and local/state efforts. Theories of interorganizational relationships, evaluations of interagency programs, and practical suggestions for individuals contemplating joint programs are included. \$5.50 per copy.
- ☐ *Making the System Work: An Advocacy Workshop for Parents.* A trainers' guide for a one-day workshop designed to introduce the purpose of advocacy, identify sources of power and the chain of command in agencies and school systems, and practice advocacy techniques. \$8.50 per copy.
- ☐ *The Multnomah County CAPS Project: An Effort to Coordinate Service Delivery for Children and Youth Considered Seriously Emotionally Disturbed.* A process evaluation of an interagency collaborative effort is reported. The planning process is documented and recommendations are offered. \$7.00 per copy.
- ☐ **NEW!** *National Directory of Organizations Serving Parents of Children and Youth with Emotional and Behavioral Disorders.* The 344 U.S. organizations in the second edition provide one or more of the following services: education and information, parent training, case and systems level advocacy, support groups for parents and/or brothers and sisters, direct assistance such as respite care, transportation and child care. \$8.00 per copy.
- ☐ *Parents' Voices: A Few Speak for Many* (videotape). Three parents of children with emotional disabilities discuss their experiences related to seeking help for their children (45 minutes). A trainers' guide is available to assist in presenting the videotape. Free brochure describes the videotape and trainers' guide and provides purchase or rental information.
- ☐ *Respite Care: An Annotated Bibliography.* Thirty-six articles addressing a range of respite issues are summarized. Issues discussed include: the rationale for respite services, family needs, program development, respite provider training, funding, and program evaluation. \$7.00 per copy.
- ☐ *Respite Care: A Monograph.* More than forty respite care programs around the country are included in the information base on which this monograph was developed. The monograph describes: the types of respite care programs that have been developed, recruitment and training of respite care providers, the benefits of respite services to families, respite care policy and future policy directions, and a summary of funding sources. \$4.50 per copy.
- ☐ *Taking Charge: A Handbook for Parents Whose Children Have Emotional Handicaps.* The handbook addresses issues such as parents' feelings about themselves and their children, labels and diagnoses, and legal issues. The second edition expands upon emotional disorders of children, including post-traumatic stress disorder and mood disorders such as childhood depression and bipolar disorder. \$7.00 per copy.

More listings and order form on reverse

- ☐ **NEW! *Transition Policies Affecting Services to Youth With Serious Emotional Disabilities.*** The monograph examines how state level transition policies can facilitate transitions from the child service system to the adult service system. The elements of a comprehensive transition policy are described. Transition policies from seventeen states are included. \$5.75 per copy.
- ☐ ***Working Together: The Parent/Professional Partnership.*** A trainers' guide for a one-day workshop for a combined parent/professional audience. Designed to identify perceptions parents and professionals have of each other and obstacles to

cooperation; as well as discover the match between parent needs and professional roles, and practice effective listening techniques and team decision making. \$8.50 per copy.

- ☐ **NEW! *Youth in Transition: A Description of Selected Programs Serving Adolescents With Emotional Disabilities.*** Detailed descriptions of existing youth transition programs are provided. Residential treatment, hospital and school based, case management, and multi-service agency transition programs are included. Funding, philosophy, staffing, program components, and services information is provided for each entry. \$6.50 per copy.

ORDER FORM AND MAILING LIST Research and Training Center

- ☐ Please send me the publications checked. \$_____ enclosed as appropriate.
- ☐ Add me to your mailing list. ☐ Take me off your mailing list.
- ☐ Change my address as noted below.

NAME _____

ORGANIZATION _____

STREET ADDRESS _____

CITY/STATE/ZIP _____

TELEPHONE _____

CHECKS PAYABLE TO: Portland State University. **PREPAYMENT REQUIRED.**

MAIL TO: Publications Coordinator, Research and Training Center, Regional Research Institute for Human Services, Portland State University, P.O. Box 751, Portland, Oregon 97207-0751, (503) 464-4040.

For your information: Our federal identification number is 93-6001786.

Portland State University
Research and Training Center
Regional Research Institute for Human Services
P.O. Box 751
Portland, Oregon 97207-0751

Change of Address?
Please send us your new address along
with your old mailing label.